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Negotiating Moral Identity with Type 1 Diabetes: Care and Contradiction in Conversations with Young Adults

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Abstract: This article is based on original ethnographic research among college students aged 18–25 living with insulin-dependent type 1 diabetes. I investigate how moral language in medical treatment settings and social environments informs patients' experiences of managing their diabetes. Moral language about choice, control, responsibility, and risk was regularly used to describe daily diabetes management habits. Young adults with diabetes internalized a moral imperative to prioritize health. This moral obligation to health contributed to participants' conceptions of self and influenced participants' characterizations of other people with diabetes (PWD). Since the mid-twentieth century, the clinical approach to diabetes care has relaxed; however, some harmful assumptions linking patient character to his or her ability to comply with a prescribed treatment regimen still circulate in the culture of type 1 diabetes care. While failing to take insulin or to check blood sugars can lead to dangerously high or low glucose levels in the body, language tying patient worth to treatment compliance fails to show the complexity of striking a balance between hypervigilance and negligence in daily diabetes care routines.

Keywords: Ethnography, type 1 diabetes, morality, young adults, care, choice

Introduction

At age ten, I was diagnosed with type 1 diabetes. The day started like any other Saturday: I woke up, ate some Rice Krispies for breakfast, and prepared for a birthday party at the movies. Preceding my diagnosis, I was eating more but losing weight, drinking water excessively, and constantly using the bathroom. I was irritable and complained every week on the way to dance class. My mom noticed these changes, and called a friend whose daughter had diabetes. She recognized my symptoms and told my mom to bring me over to have my blood sugar tested using her daughter's glucometer.

Once we arrived at our friend's house after the party, I was terrified of having my finger pricked. The glucometer read CRITICAL HIGH, signifying that my blood sugar was above 500 mg/dL, and could not be calculated by the machine. Blood sugar levels for people without diabetes typically do not rise above 140 mg/dL within two hours of eating a meal (IDF 2007). Thus, with a blood sugar above 500, something was wrong. We cried the whole drive to the hospital, where I stayed for four days. A team of healthcare providers stabilized my condition, and taught my parents and me how to test my blood sugar, count carbohydrates, and give insulin shots.

I could not participate in the annual standardized testing at my elementary school that year and I assumed I would make it up another time. However, when I returned to school this was not the plan. As a conscientious fourth grader who emphatically monitored her academic progress, I was frustrated that my hospital visit prevented me from receiving affirmation of my identity as a "good" student. I have since recovered from this disappointment, but a fixation on measurement has long permeated my self-management of diabetes.

The use of letters and numbers as indicators of academic achievement in the American education system has created a moral hierarchy of reward and punishment meant to commend students who adhere to guidelines promulgated by teachers. Students who do not excel according to these guidelines are given grades labeling them as lazy or stupid. I rely on a normative definition of morality in this paper as defined by the *Stanford Encyclopedia of Philosophy* (Gert and Gert 2016). In this sense morality is defined as "a code of conduct that, given specified conditions, would be put forward by all rational persons" (Gert and Gert 2016). The normative moral guidelines for diabetes care, including the measurement of glycated hemoglobin for people with diabetes (PWD), called HbA1c, parallel the moral hierarchy of the education system. Patients with A1cs above the range recommended by the American Diabetes Association (ADA) may be labeled out of control by health providers and peers. These recommendations are intended to prevent complications of poorly regulated blood sugars, including deterioration of nerve, kidney, and eye functioning. Adults aged 18 and over are recommended to maintain A1c levels below 7.0%, denoting an average blood sugar of 154 (ADA 2016).

The language of the A1c implies a moral duty for patients to behave responsibly to preserve health. The ADA notes that "targets must be individualized based on a patient's circumstances," and healthcare providers advise that one's A1c is "just a number" (ADA 2016). These phrases purport a clinical migration toward flexibility: nevertheless, for those interviewed, the underlying premise of the A1c is that health is an objective good (Kirkland and Metzl 2010; Mulligan 2014). While no one would argue persistent high blood sugars are desirable, immense emotional weight rests on the receipt of a "good" A1c.

In *The Logic of Care*, Annemarie Mol (2008) discusses how emphasis on patient choice in healthcare discourse fails to recognize the social and corporeal constraints of life with chronic disease, holding patients morally liable for failure to achieve control. Mol defines care as "a calm and persistent, but forgiving effort to improve the situation of a patient, or to keep this from deteriorating" (2008, 20). She discusses numbers as normative "fact-values" that are frequently mistaken as objective parameters, producing distress for patients (Mol 2008, 44). Her explanation of numbers and their lack of neutral value lends itself to discussion of the morally charged A1c. It would follow that the time preceding receipt of A1c results is often filled with worry. Do I have a reasonable explanation for why my blood sugars were not in control? How will my parents or doctor react? This idea of control, and the blame that befalls a person with chronic illness considered out of control, is paradoxical, as the nature of type 1 diabetes is that one's pancreas no longer controls the metabolic processes for which it is responsible. This paradox is

particularly relevant during the young adult period, as responsibility for diabetes management shifts almost entirely onto the increasingly independent patient, whose social supports such as parents may occupy a smaller role in his or her daily care routine (Anderson and Wolpert 2004).

A great deal of research into clinical and self-care for diabetes has established daily management practices as fraught with morally charged activities described in value-laden terms by family members, providers and public health officials (Borovoy and Hine 2008; Broom and Whitaker 2004; Ferzacca 2000; Mol 2008; Oldani 2010; Rock 2010). This research demonstrates a population's departure from assumed perceptions of risk, autonomy, responsibility, and choice defined through the lens of a consumer model for biomedicine. This model celebrates discipline, informed-choice, and risk-prevention—activities that tend to break down in self-care practices, while the care-based model attempts to reconceive this notion of choice in chronic disease management (Mol 2008). This research has primarily focused on patients with type 2 diabetes, who have long been moralized based on socially constructed assumptions that lack of self-discipline and overindulgence in food resulted in their obesity and ill health (Borovoy and Hine 2008; Broom and Whitaker 2004).

Through interviews with young adults with type 1 diabetes, I investigate how nine young adults have experienced moral language. I depart from the significant body of literature about type 2 diabetes to evaluate self-understanding negotiated through the lens of life with type 1 diabetes. Young adults are fascinating because they encounter new levels of freedom and responsibility as they transition to adulthood. Interviews with this sample revealed an internalized moral imperative to prioritize health, and provided support for a more caring—as opposed to consumerist—model of chronic disease management as espoused by Mol (2008). Based on review of existing literature, evidence from interviews, and autoethnographic commentary, a perceived duty to preserve bodily wellbeing as the highest good contributes to participants' conceptions of self, generates internal conflict, and influences participants' characterizations of others with diabetes.

The Moral History of Diabetes Care

To provide context regarding moralization in diabetes care, it is necessary to understand how management ideals developed following the discovery of insulin in 1922. In *Bittersweet,* Feudtner (2003) describes the transmutation of type 1 diabetes from an acute to chronic illness and investigates Dr. Elliott Joslin's role in developing care practices through analysis of scrupulously maintained patient records. Joslin, the first doctor to specialize in diabetes in the United States, made it his mission to improve health and prolong life for PWD by sending them on an arduous quest to exercise control in every aspect of life. Feudtner describes Joslin's philosophy of care as "marked by a strong Protestant work ethic, a zealous attention to detail, and high regard for self-control" (2000, 64). He embraced a paternalistic model of the physician-patient relationship, employed morally charged language in discussions about and with patients, and failed to understand why patients might not follow his rules (Emanuel and Emmanuel 1992; Feudtner 2003). Joslin required patients to arrange their lives around testing urine for glucose, eating meals on

a strict schedule, and injecting the right amount of insulin at the right time (Feudtner 2003). These original tasks have evolved to include testing daily blood sugar levels using a glucometer, changing insulin pump infusion sets, and inserting Continuous Glucose Monitor (CGM) sensors to track blood sugar levels. A cure they are not, but these technical improvements have increased flexibility in diabetes care.

Changes in standards of care demonstrate a departure from Joslin's interpretation of diabetes care as a moral obligation to live an ascetic lifestyle. Joslin was content with supervising more than disease-related aspects of his patients' lives (Feudtner 2003). His emphasis on strict regulation of exercise, diet, and insulin as crucial to achieving "victory" over diabetes has had a bittersweet legacy for the lived experience of diabetes. His guidelines imply that PWD must care for themselves, and those who stay the course will escape debilitating complications such as eye, nerve, and kidney damage. Unfortunately, he could not guarantee that those with the strictest regimens would avoid long-term complications, even with medical technological advancements. The results of the Diabetes Control and Complications Trial (1996), which studied whether strict management practices were the best method to preserve health and avoid complications, proved Joslin's philosophy of care scientifically relevant posthumously. However, questions regarding patient quality of life under rigorous care expectations as well as evolving views concerning physician authority produced ambivalent responses to these results. Ambivalence continues to permeate the lives of PWD who are challenged by striking a balance between pursuing health without forfeiting a satisfying life. While diabetes care has changed over time, Joslin's moralization of treatment remains alive through a perceived duty to manage risk and a culture of ceaseless measurement.

Methodology

The purpose of this study was to evaluate how moral language is used in diabetes care practice for college students aged 18–25 living with type 1 diabetes. Drawing on topics from other ethnographic accounts of diabetes management, I employed qualitative research methods to analyze how ideas about choice, control, responsibility, and risk contribute to moral language implicit in diabetes care practices, and the impact of this language on personal identity and quality of life.

Prior to recruiting participants, I obtained approval for human subjects research from the Providence College Institutional Review Board. I use pseudonyms to protect participants' identity and avoid revealing personally identifiable health information. I utilized convenience sampling and identified participants through my personal network, including friends and acquaintances affiliated with the diabetes community through the nonprofit College Diabetes Network.[1] Using text message, email, social media, and word of mouth, I explained to prospective participants that I was studying the illness experiences of college students with diabetes. Interviews were scheduled in convenient locations or conducted through Skype video chats. They were informal and lasted between one and two hours. I employed a semi-structured, open-ended method directed by an interview guide I designed to collect information about participants' lives (Crabtree and DiCicco-Bloom 2006). Topics ad-

dressed during the interviews included relationships, health practices, education, employment, interactions with health providers, social supports, and personal beliefs. Interviews were audio-recorded using a smartphone and laptop computer, and transcribed by hand. Having considered a range of existing literature, interview transcripts were manually reviewed to identify common themes among interviewee responses and to pinpoint areas of ambiguity that require further inquiry, thus employing deductive analysis. Participation in the interviews was voluntary, and no incentives were offered.

As a friend of many of the participants, they were aware of my status as an undergraduate student with diabetes. Due to my personal connection to the topic, I incorporated autoethnographic evidence.[2] Autoethnography enriches the epistemological soundness of the study results by better contextualizing participants' experiences for cultural outsiders through my subject position as a cultural insider (Ellis et al. 2011). By acknowledging my lack of neutrality toward the topic of interest and employing the reflexive approach to anthropology, I reinforce the theoretical relevance of study participants' narratives by providing a distinctive interpretation of the lived experience of chronicity that a person without diabetes could not provide. Malterud explains reflexivity as how an author's subject position influences "what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions" (2001, 483–84). My collection and analysis of participants' responses was done through triangulating existing literature, participant interviews, and personal experience with diabetes.

The sample consisted of four males and five females. Seven participants were currently enrolled at an American four-year college or university, and two had recently graduated. All participants were white and shared general class cohesiveness, as all but one participant indicated consistent access to health insurance through their parents and reported seeing diabetes care providers at least annually (Table 1).

Requiring that interviewees be enrolled at a college in the United States limited educational and socioeconomic diversity of the group. I recognize that this sample is not representative of the true level of diversity in the undergraduate student population. While the global incidence of type 1 diabetes has been increasing since the mid-twentieth century, this increase is less pronounced in the United States than other countries (Maahs et al. 2010). Some evidence also points to a higher prevalence of type 1 diabetes in non-Hispanic white youth in the United States, which may have further diminished the diversity of the sample (SEARCH for Diabetes in Youth Study Group 2007). Participants exhibited positive outlooks on life with diabetes. All felt generally supported by their friends and family, indicating "stable psychosocial resources," which has been associated with improved blood sugar control over time and has positive implications for mental health status (Peyrot et al. 1999; Rock 2010). I anticipated low diversity, but I did not expect most participants to fit a rather normative standard of a "good" PWD.

Table 1: Participant profiles.

Average Age of Participants at Diagnosis	12.4
Age Range of Participants at Time of Diagnosis with Type 1 Diabetes Mellitus	2–18
Average Number of Years Lived with Diabetes	8
Range of Participant Years Lived with Type 1 Diabetes Mellitus	2–19
Family Makeup (Heterosexual, Two Parent Household)	9/9
Positive Comorbid Neuropsychological Diagnosis (e.g., ADD/ADHD, Anxiety, OCD, Bipolar Disorder)	6/9
Positive On-Campus Residence Status	6/9
Positive Family History of Diabetes	1/9
Existing Ties to Diabetes-Related Organizations (e.g., CDN, ADA, JDRF)	8/9

As a newcomer to medical anthropology, the study was limited by the learning curve and uncertainty of how my subject position influenced participants' answers to my questions. I empathized with interviewees' experiences and appreciated their enthusiastic responses. As I felt more comfortable during interviews, participants seemed more comfortable sharing their formative experiences, with and without chronic illness.

Discourses of Diabetes Management

The historical progression of diabetes treatment and technology offers a partial view of the moralization of diabetes. Though Joslin's philosophy of care has been reinforced by results of clinical studies, his strict guidelines have had a conflicting legacy in the lives of PWD. Through interviews with young adults, I uncovered lasting evidence of Joslin's puritanical approach in the colloquial language of chronic care.

A Duty to Care

Liz is a sophomore at a small college in the northeastern United States, majoring in political science and women's studies. She was born in New England, but now lives in the South. On recesses from school, Liz lives with her parents, with whom she shares a close relationship. She was diagnosed with diabetes at age six, after beginning to wet the bed and experiencing unquenchable thirst. Her mom recognized these symptoms—as she also has type 1 diabetes—and tested Liz's blood sugar using her meter.

> I remember the number. It was 235. I had eaten a piece of cake the night before, and my mom didn't always eat sugar, because of her diabetes. And I said, "Oh Mommy, I'm like you, I probably shouldn't have eaten the cake!" And she responded, "Yeah you're right, you are like me now" but I didn't connect it. Then she said, "It's not because you ate the cake."

Diabetes can be diagnosed in a variety of ways, but in a patient with classic symptoms, a random plasma glucose test greater than 200 mg/dL typically indicates diabetes (ADA 2016). Liz's mom took her to the doctor to be officially diagnosed. The doctor discussed the basics of diabetes—blood sugar testing, carbohydrate counting, insulin injections—and explained that Liz would need to monitor her diet and be on the lookout for high and low glucose. Liz's description of her doctor's advice reflects the moral duty to care for oneself that accompanies a diabetes diagnosis. A qualitative study of type 1 diabetes patients in Finland found that patients felt a responsibility to themselves, their families, their doctors, and society to work hard to prevent emergency situations and negative health outcomes by managing risks on a daily basis (Hirjaba 2014). These duties range from remembering to carry your insulin, glucometer, and snacks for low blood sugar, to wearing a medical identification bracelet. All participants employed similar language implying that lack of awareness of yourself and your surroundings as a PWD is unacceptable. Liz discussed the challenge of remembering the bag she used to carry her supplies.

> Having diabetes made me grow up faster. I had to be more responsible, remember things. I would get yelled at because I used to forget my purse. I would forget it on recess or in my locker. But it was hard for me to remember it.

Another participant, Ann, a recent graduate who has had diabetes for four years, also cited that diabetes gave her a duty to care.

> A big part of having diabetes is making sure you're always healthy, you're always doing it right.

Variations of Liz's and Ann's narratives were present in every interview. These responses affirmed that participants felt a moral injunction to choose responsibly and prioritize health.

Participants' accounts reflected a consumerist biomedical culture that assumes patients act rationally to mitigate health risks and prolong life (Borovoy and Hine 2008). While failing to take insulin or check blood sugars can cause life-threatening glucose levels, this neoliberal conception of patients does not acknowledge unpredictable events, human error, and conflicting patient values. Nor does it recognize the emotional suffering that accompanies imperfect choices that can produce undesirable results, as Mol (2008) explains in her criticism of the logic of choice. Ann reported agonizing over food choices and insulin-dosing decisions.

> It's so involuntary now for me to check my sugar and give myself insulin. There are times when my sugar gets low or high and I'll start questioning what I did. Did I overshoot my insulin? What did I do to mess this up?

Ann's description of management practices as "involuntary" calls into question the decision-focused rhetoric of the neoliberal conception of patients. Thus, neoliberal ideologies create unrealistic expectations that autonomous patients who act in accordance with a normative standard of diabetes care will achieve precise results. These unrealistic expectations then translate to an increased pressure for patients to seek control of more than just blood sugars.

My conversations with James and Ann about alcohol demonstrated this tension. James is a junior studying management at a large university. He works two jobs, participates in student government and a fraternity, and volunteers in the community. James was diagnosed with diabetes days before he would have left for his freshman orientation at another school farther away from his childhood home. Diabetes deterred his original plans and spoiled his dream of becoming a US Marine.[3] As James was diagnosed approximately two years prior to our interview, he still considers himself in the "honeymoon period," a phase where the pancreas remains partially functional. This phase is characterized by more stable blood sugar levels. James considers himself healthy aside from having diabetes: he exercises regularly and eats a well balanced diet. Despite his dedication to living a healthy life, James' loved ones still worry about him. Sometimes this care holds James and others living with diabetes to higher standards of managing risk.

As risk management chair of his fraternity, James cannot drink at most fraternity events, and opts not to drink when he feels out of control. However, like many college students, James is inclined to occasionally test his boundaries.

> "James, you're the scariest person to drink with" my fraternity brothers say. But they're team players so they take care of me.

James appreciates their concern, but his choice reflects a complicated value judgment and shows desire for social inclusion—as opposed to blatant disregard for health. James' circumstances resonate with Borovoy and Hine's (2008) discussion of moral language in the treatment of elderly Russian immigrants with type 2 diabetes. Their American doctors deemed them difficult and noncompliant because they chose to continue drinking vodka and eating traditional foods. Noncompliant meant that the patients failed to adhere to the treatment regimen of diet and lifestyle recommendations. The assumption underlying the doctor-patient relationship in diabetes management that patients are fully autonomous, prioritize avoiding risk, and will make choices to preserve health at all costs does not adequately account for the plurality of patient social and cultural values (Borovoy and Hine 2008; Emanuel and Emanuel 1992). For James and the Émigré population, the impetus driving their "noncompliant" behavior is often synonymous with the free choice and individualism that inform the American culture of biomedicine in the first place (Borovoy and Hine 2008; Ferzacca 2000). While James drinks as part of his social experience of college, and the Russian Jewish Émigrés refuse to alter their diets upon emigrating to America, they should not be classified as careless. Instead, these circumstances show the complexity of life with chronic illness as well as the incomplete picture of the emphasis on choice alone.

Blaming patients who fail to act in ways deemed rational and desirable by American biomedical culture can send harmful messages about personal capacity for self-control and the value of one's character. Too heavy a burden to choose wisely prevents patients from adapting to fluctuating physical and emotional needs of life with chronic illness (Anderson and Wolpert 2004, 348). Ann describes the challenge of reconciling competing interests in relationship to drinking, facing criticism from peers for choosing not to drink, and receiving pressure from her parents to act more carefully than her siblings.

> My parents say, "We worry about you more because of the diabetes" compared to my sister and brother. And I'd ask why? It's gotten better, they know I make good decisions now because they can see it, but it was really hard because I felt, I've given you no reason to not trust me, or not to think that I'd be ok. So I wasn't sure why they felt that way?

Ann is a person with diabetes and a young adult seeking social inclusion. Mulligan discusses the dysfunctional nature of neoliberal health policies that assume complete patient autonomy and omniscience for "consumers" in the health "market" (2014, 89). She claims that assumptions about "carefully calculating consumers" do not take into consideration the "moral and social criteria that people actually employ when making decisions about their health

care," and that the consumer model does not account for how people respond to illness (Mulligan 2014, 90). Ann's situation shows the complexity of criteria used to inform decisions, and the contradictory interests of peers, parents, and self that blur lines of free choice. While none of these young adults can speak to the experience of parents of children with diabetes, Ann's experience also illustrates the increased pressure PWD feel to measure up to the expectations of themselves and those around them.

Measuring Up

Living with diabetes is a constant game of numbers: I test my blood sugar several times a day, count the carbohydrates I eat, and adjust my insulin intake according to a set of ratios my doctor and I have discussed. The objective is to stabilize my blood sugars to fend off neuropathy, nephropathy, retinopathy, and other daunting consequences of persistent high blood sugar. I assess how I feel throughout the day, and rely on a CGM, which measures my blood sugar every five minutes to alert me if I am above or below the numeric thresholds I have set it to measure.[4] While this acute self-awareness may translate to tighter regulation of diabetes and a more detail-oriented approach in other areas of life, it comes at a cost to self-acceptance. Diabetes management is a process of constant striving. While the struggle to achieve stellar results, especially as related to one's health, seems a worthy cause, it is difficult to determine when to accept that enough effort has been put forth toward a goal. The implications of constant monitoring are palpable in the guilt that participants described feeling at the doctor, when forced to face the numbers.

In *Prescribing by Numbers*, Greene (2007) elucidates how numbers often supersede patient and physician perception in the diagnosis of various diseases. While physical perception remains relevant throughout the lifespan in diabetes due to symptoms produced by fluctuating blood sugars, measures such as the A1c and CGM have allowed for extensive collection of empirical data, which can paint a picture of a patient's daily blood sugar control and inform a patient's conception of self-efficacy. These measures allow for evidence-based treatment adjustments, and with the CGM, lessen the responsibility of the patient by automatically recording blood glucose data in real time. Nonetheless, emphasis on numbers was concerning for Nicholas, a graduate student who was diagnosed with type 1 just before his freshman year. Feudtner (2003, 15) explains that PWD express concerns about how they are perceived by their peers and doctors, and that these worries influence patients' lived experiences and relationships with medical providers. I asked Nicholas if he had ever manually falsified his blood sugar records before going to the doctor, and his response echoed Feudtner's claim.

> I have to write down my blood sugars. At first, it's not too bad, but it's annoying when you have to go through at the end of each day and write everything. It's easy to forget. So how did I get away with it? There was one month that I actually did it, I wrote down my numbers. Then I was reminded that I had the endo [endocrinologist appointment] coming up and thought to myself "I haven't been keeping track. I'm screwed." So I took my last visit's

> numbers, and wrote them out on an excel spreadsheet, because my doctor hadn't seen it in that form, then I presented it to him, and he bought it. I save it on my computer and those are my default blood sugars. It's bad, but this past month I didn't have time for this blood sugar nonsense. I changed the dates, I fudged the numbers, and I went to my doctor.

Nicholas' story shows the lengths that some go to represent themselves in a way that meets social expectations. He demonstrates how numerical evidence can be subject to human interference, but is also an example of the complex relationship between PWD and their numbers. Nicholas' account depicts the challenge of diabetes management in practice, as described by Mol: "In practice daily care turns around messy, material, smelly, bloody, frightening, or tedious activities that tend to be difficult to do (for professionals as well as patients). Choice has very little to do with all of this" (2009, 1756). Mol (2008) asserts that a mischaracterization of health-related decision-making has led to a poorly-thought-out adoption of the "logic of choice" in healthcare. This model fails to recognize the physical and emotional constraints of human existence with disease. Mol (2008) advocates for a transition from this consumer model of medicine to a "logic of care," which would necessitate patients and providers accepting that flawed treatment practices and technology make it impossible to achieve total control. Nicholas' story illustrates the tension between trying to preserve and live life simultaneously.

Nicholas was the only participant who falsified his records, but other participants had anxiety about reviewing records at endocrinologist appointments. Liz described a cycle of guilt and self-doubt tied to her A1c. She finds her experience with grades analogous to receiving A1c results.

> Getting Bs in my classes makes me want to pull my hair out. I think, I need to work harder, I need to do better, I need to get this right. I'm still scared sometimes to go to the doctor. Because I know that A1c number is not gonna be what he wants it to be. I don't know what I'm afraid of. It's not like he is going to do anything to me? He's a really nice guy, and he doesn't yell at me either. It's a disappointment look almost—that kills me.

Liz says she feels guilty and disappointed in herself frequently during doctor's visits.

> When my blood sugar is high, I'll kick myself about it. I'll think, "Oh I shouldn't have eaten that." But I wanted to? I haven't had dessert this whole week, and then I have one thing of ice cream, and I tested an hour later, and it's high. It's annoying. It kind of furthered my own kind of self-doubt thing.

While Liz's perfectionist tendencies were more pronounced than some of the others I interviewed, several participants revealed their struggles with separating their numbers from self-perception. Interviewees noted feeling anxious when their blood sugar is out of range, likely a combination of the physiological effects of unruly blood sugars and the burden of personal responsibility.

Liz and other participants also mentioned premeditating justifications for their numbers prior to seeing the doctor.

Perfectionism raises concerns that a patient will reach a breaking point where they become unable to care for themselves, often termed "diabetes burnout." Frustration with managing diabetes lies in "the fact that 'good' behavior does not always translate into good results" (Snoek and Skinner 2006). Burnout is a state of distress occurring when a person may develop self-destructive management habits as a result of feeling overwhelmed, depressed, anxious, or apathetic toward their diabetes-related responsibilities (Gebel 2013). While no participants reported experiencing burnout, burnout presents itself as a blend of mental health concerns (e.g., depression, anxiety), but is unique to PWD as it arises from the demands of chronic disease management.[5] Impractical treatment goals and lack of understanding by parents or providers can lead to a culture of "perfectionism," leaving young adults more susceptible to burnout (Anderson and Wolpert 2004, 348). Moving toward Mol's definition of care as well as extracting choice-focused rhetoric from daily care practices might offer a solution for burnout. Engaging in this type of care would accept the unpredictability of chronicity and allow patients to adapt to fluctuating states of physical and emotional need.

No interviewees reported that their doctors were stern during appointments; however, despite participants' best efforts to separate sugar levels and moral character, their narratives of guilt and disappointment showed that this is an ongoing challenge. Patients are not alone in their frustration with diabetes as a game of numbers. Oldani (2010) discusses the danger of treating patients as "relative value units" in an incentivized, corporate compliance model. He describes the potential for blocking access to medical care for type 2 diabetes patients who do not have the right numbers by linking physician compensation to patient A1c's, among other measures (Oldani 2010, 220). Doctors were encouraged to discontinue seeing "bad" patients with diabetes, which presented them with a unique ethical dilemma (Oldani 2010).

Another study evaluated the existence and impact of moral language with respect to people living with type 2 diabetes who "described a culture of surveillance and monitoring" of their activities by themselves and third parties to ensure they were following prescribed treatment regimens (Broom and Whitaker 2008, 2374). These authors interviewed adults with type 2 diabetes and found that they struggled to achieve a balance between submitting to strict care routines and asserting autonomy as independent adults. The results showed that participants often equated "good" with "exercising restraint" and self-regulation in diabetes care practices, while being "naughty" was equated with "diverging from the recommended regimen" (Broom and Whitaker 2008, 2377). Using these morally charged terms to reference compliant or deviant behaviors was found to lead to a sense of diminished agency for adults with diabetes who have had to transform their conception of responsibility in response to their condition. Participants characterized themselves in childish ways or reduced non-compliance to immaturity to transfer guilt they felt from failing to adhere to prescribed treatment regimens. Furthermore, the language recorded in interviews reflected a biomedical culture praising control, denoting states of being out of control as evidence of "moral failing," similar to the implications of Joslin's philosophy (Broom and Whitaker 2004, 2381). Though this study evaluated people with type 2 diabetes, many of its

themes resonated with young adults who have type 1 diabetes—but not in the way I anticipated.

Prior to starting interviews, I expected participants to experience similar phenomena to the participants in Broom and Whitaker's study. This might include infantilizing narratives and questioning of self-discipline—such as others asking "Can you eat that?"—from family, friends, providers, or strangers with little understanding of diabetes. Instead, I found participants mostly denied experiencing judgment from third parties. Almost all participants employed "stigmatizing rhetoric" toward peers with diabetes and themselves (Metzl 2010, 5). Sociologist Erving Goffman (1963) developed the concept of stigmatizing rhetoric, which claims that to affirm you are healthy, you must find a way to establish that another person is unhealthy. Participants employed varying degrees of moral language to describe "good" patients as healthier than other presumably "bad" patients. For example, James shared his opinion regarding online networks for PWD.

> When I was first diagnosed, I thought it was cool, I joined all these online websites. I got an email today from one. … I hate it. It's stupid. I don't know, I think they are more for people that don't know how to control themselves and don't have a life outside of diabetes.

This quote displays stigmatizing rhetoric, as James characterizes people who participate in online diabetes groups as people who fail to take care of themselves. James also engaged in self-moralizing during our conversation.

I found myself using stigmatizing rhetoric too, measuring up how many times in a day I typically test my blood sugar or how often I forget to take insulin, in relationship to whom I was speaking. This occurred extensively with James in discussing his recent A1c, which happened to be 6.2%. Without even thinking, I commended James for his accomplishment. It sparked jealousy at first, then an onslaught of perfectionist leaning thoughts about my complacency and need to improve my own A1c. I struggled with this conversation. I recognized James as worthy of praise because the exercise and food habits he previously described to me in the interview signaled that he earned his A1c. But as I listened forward, even James began to self-moralize.

> I'm cheating a little. I'm technically still in the honeymoon period. My Lantus [type of insulin] is on 10 units, and I only have to take—I take 1 unit for every 20 grams of carbs. So, I cheated a little bit.

His disclosure stimulated a comparison of our carbohydrate ratios and insulin sensitivity factors. Discussing these numbers revealed their lack of objective value and validated the culture of surveillance of others and oneself. Furthermore, my own rationalization that James deserved his A1c was a moral judgment of his work ethic, which proved relevant to how participants defined themselves.

Defining a Self with Diabetes

Most participants emphasized the quality of their work ethics and expressed desire to dissociate diabetes from public identity. Some feared being labeled as lazy or weak of will because they could not meet others' and their own expectations. Liz discussed this frustration with her experience playing field hockey.

> I'm a hard worker, and I wanted to give it my all, but sometimes I couldn't because my blood sugar was dropping and I couldn't run however many miles. One day we were doing a really hard workout and my sugar was low. So I sat down, let my coach know, and started eating. There were girls on my team who thought I used diabetes to avoid working out. I felt judgment that the reason I worked so hard was to compensate.

Liz was upset that diabetes detracted from her identity as a committed athlete. Mol addresses this problem in her discussion of the citizen patient: "By definition, citizens are not troubled by their bodies . . . a citizen is someone who controls his body, who tames it, or who escapes from it. But this implies that you can only be a citizen in as far as your body can be controlled, tamed or transcended. Disease interferes with this" (2008, 31). This definition of a citizen and idea of choice, especially in a disease state, reflects the most significant challenge for study participants: understanding identity in the context of chronic illness that interferes with parts of life subject to moral judgment and often beyond their control.

Liz's unease about being perceived to have a diminished work ethic because of diabetes was ironic though, as all participants cited that diabetes had shaped their character, or in James' case, catalyzed their motivation and leadership skills.

> I was never a control freak before I had diabetes. Now, I have to be the leader of everything. I was always a leader. I was always on executive boards of everything, but never the president. I'm realizing that I do have all these leadership qualities—but I didn't have that until I was diagnosed.

James' self-awareness demonstrated a culture of surveillance transformed into self-reflection. When asked if they retained a personal philosophy about living with diabetes, most participants provided immediate answers, and some even cited specific quotes. James' quote was: "Improvise, Adapt, Overcome." This quote guides his thoughts and actions and he has found it useful in his adjustment to diabetes. Mol (2008, 79) explains that guilt accompanies the logic of choice in healthcare, because patients make decisions and are considered responsible for all consequences. She calls for replacing the logic of choice by reclassifying patient action as activities instead of decisions, and accepting aspects of disease that escape control (Mol 2008). Many participants struggled to detach themselves from numbers and accept limited capacity for control, but James accepted his responsibility and did not consider himself morally suspect based on his numbers. When asked if he felt personally

responsible for out-of-range glucose levels, James' responded as follows:

> I see a number, and I think all right, this is what I have to do to get back to normal. When I was at 500, I thought, I clearly know what caused this, great. Now let's go back to normal. I see it as solving a problem. I don't think about it with any emotion. I think about it more logically.

On one hand, James avoids self-moralizing in this process, but on the other hand, his detached method of problem solving resembles apathy. James, Nicholas, and several other participants cited approaching their diabetes care in a detached, logical fashion, but unguarded excerpts from Liz's and Ann's interviews offered another illustration of the varied reactions to chronic illness.[6, 7]

Conclusion

Life with diabetes has evolved with changes in treatment and technology. Early care practices, which emphasized a normative standard of right action, framed health as an unqualified good worthy of pursuit at any cost (Feudtner 2003). The attitudes of participants and their positive experiences with providers show how clinical culture has attempted a more "caring" approach and sought to detach blame from patients. However, the internalized moral injunction that participants displayed through perceived obligation to manage risk, hyper-meaningful interpretation of numbers, and reflections on their conditions' influence on their lives shows how health functions as a source of moral judgment. The elusive quest for control through responsible decision-making according to neoliberal conceptions has generated anguish for patients who internalize pressure to manage their condition, and also influences other areas of their lives. Liz's and Ann's narratives of distressed decision-making as well as James' disinterested approach to solving problematic blood sugars support Mol's argument for dissociating the logic of choice from tending to chronic disease. Based on the ethnographic data and analysis of existing literature, distancing blame from care activities and a more compassionate approach to diabetes management are causes worthy of increased pursuit.

Joslin's philosophy of care led him to create "Victory Medals," which were awarded to PWD who survived with diabetes for 25 or more years and who were deemed to be in good health after thorough physical examination, for their unflagging commitment to a strict diabetes regimen (Feudtner 2003, 175). The diabetes community expressed mixed reactions to this system of moral hierarchy, as tying patient willpower and ability to follow a doctor's orders to health outcomes assigned immense blame to PWD. These awards imply that those who develop long-term complications are negligent and thus deserving of a deteriorating health status. The medals have since been modified to reward longer periods of time lived with diabetes and continue to be granted through various outlets (Nauen 2014). While these medals might serve as incentives to prioritize health, the idea that choosing steadfast commitment to medical care can defeat diabetes is misleading. Chronic care does not lead to cure, and rigorous care may not lead to escaping

diabetes complications (Feudtner 2003; Mol 2008).

I recently received a variation of a Victory Medal for living ten years with diabetes. While this required no physical certification of health, the letter of congratulations I received commemorated my "outstanding accomplishment" and applauded my "discipline in maintaining a healthy lifestyle." This language is unsettling. The culture of achievement embodied in "Victory Medals" perpetuates the faulty assumption that diabetes can be mastered through good choices—a far too simplistic view of chronic disease management that may spoil the identity of people living with diabetes.

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Notes

1. I use the term *diabetes community* to refer to people and interest groups that professionally focus on diabetes or are personally impacted by the condition.
2. See Ellis et al. (2011) and Ngunjiri et al. (2010) for further information regarding the development and practice of autoethnography.
3. PWD have historically been prohibited from entering the military. Some exceptions have been made for people who are diagnosed after entering the military, but they must receive approval by a medical board (Neithercott 2013).
4. For information regarding blood glucose monitoring technology, see Clarke and Foster (2012).
5. Diabetes burnout or distress, though a blend of various mental health concerns, is considered a separate mental health issue tied to living with chronic disease. While participants' neuropsychological conditions and experience of diabetes may be interrelated, the scope of this study did not allow for proving any relationship between these participants' comorbid conditions. See Li et al. (2008) and Lin and Von Korff (2008) for more information regarding diabetes and mental health.
6. I noticed a trend in the interviews that male participants exhibited less concern with managing diabetes than female participants. This study is too small to make claims about the broader population, and I do not intend to perpetuate gender stereotypes based on social constructions of expected gender behavior, but some evidence exists claiming that levels of diabetes-related worry were lower in adolescent boys than in adolescent girls (Hoey et al. 2001). More in depth analysis of this question of gender difference in response to chronic disease was not within the scope of the study; thus I cannot provide any conclusions.
7. Another variable that emerged, but was not central to the research question, was the impact of years lived with diabetes on a person's self-care practices. My sense is that this has an impact on approach to diabetes management, but this study was not designed to track this variable. Further research could analyze this to better contextualize participant responses.

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